# A Submission to the Legislative Council Standing Committee Legal and Social Issues Inquiry Into End of Life Choices.

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# **Executive Summary**

This submission supports law reform to provide the right of medically assisted dying for the terminally ill and addresses points 2 and 3 of the Terms of Reference.

It focuses specifically on negating the claim of those opposed to such legislation that it is impossible to draft safeguards to prevent abuse or prevent people from pressuring the vulnerable into an early death for their own selfish motives.

In an attempt at brevity, I confine the focus to three, key sources of evidence:

- 1. Victorian Medical Treatment Act 1988 (In operation for 25 years with no complaints, charges or prosecutions in regard to the safeguard Section 5f.)
- 2. Switzerland (The longest-standing jurisdiction allowing assistance to die for over 70 years. Its Government notes the theoretical abuses have not eventuated and are effectively prevented by Swiss law. 1)
- 3. Oregon (The next longest 18 years. The evidence from 18 years of official reports contradicts the assertion that assisted dying cannot be regulated with effective safeguards.<sup>2</sup>).

Each one contradicts the feared prediction. Taken together, they clearly refute the assertion that safeguards cannot be formulated to protect the vulnerable.

Alarmists however, persist in repeating this unsupported assertion. Placing ideology before evidence they wilfully or otherwise, distort the facts in an attempt to stave off change.

The overwhelming majority of us want change - the right to medical assistance for a peaceful death if we so choose.<sup>3</sup> Part of that motivation is not just a personal one but a loving one to spare those close to us having to look on as helpless spectators and endure the agony of unnecessarily prolonged suffering. It is utterly unworthy of those opposing reform to distort this and assert that assisted dying leads to a growing sense of a duty to die.

The status quo is just not an answer. In the absence of legalised assistance, too many Australians are taking their own lives violently and alone while some doctors are <u>unlawfully</u> assisting people to die. <sup>4,5,6</sup> This will become more widespread under the twin pressures of aging population and advances in medical technology. A small section of society clinging to an unsupported fear of reform is no justification for inaction. The current options are not acceptable and not covered by any safeguards that a Bill would provide. The committee should visit the overseas jurisdictions to weigh up the truth about safeguards and assess <u>first hand</u> if decriminalisation works.

#### Introduction

We have never lived so long or died as slowly as we do today. When we look ahead, most of us do not like what we see. Extended life-spans mean that we are more likely to die from the ravages of degenerative diseases with a lengthy period of debilitation before death. Many of us have watched our parents or grandparents go through this. The majority of us don't want to endure this ourselves. We know that despite palliative care, there is some chance that we may die an agonisingly slow, lingering death with our family as helpless spectators to the tragic event.

Between 70 and 85% of Victorians support such law reform to enable medically assisted dying (voluntary euthanasia). For decades, the will of the people has been overwhelmingly evident in <u>numerous opinion polls</u>. Opposition to such change however relies partly on the argument that in legislating for voluntary euthanasia, it is impossible to draft safeguards to prevent abuse especially of the vulnerable.

This submission contends that, to the contrary, safeguards when built in to assisted dying legislation, not only <u>can</u> work well, they <u>do</u> work well... as evidenced in an increasing number of jurisdictions where the law now permits assisted dying. The track records of places like Oregon, Washington, Montana, Belgium, Netherlands and Switzerland bear testimony to this and expose the Henny Penny alarmist cry as false. The sky will not fall in if Victoria legalises medically assisted dying.

1. Victorian Medical Treatment Act 1988. The Medical Treatment Act was enacted in 1988 to enable Victorians the right to refuse medical treatment. Opponents of the legislation at that time are said to have raised similar alarmist concerns - that to allow such a right (to refuse medical treatment) would open the door to relatives pressuring the weak and vulnerable into an early death.

Let me quote here extensively from an article "<u>Duress on the 'vulnerable' to end their lives</u>" by Dr. Rodney Syme who points out that such claims were made without a shred of evidence to support them and that "such claims ignore the fact that vigilant doctors tasked with assessing requests for assistance do not have any difficulty in determining why a request is being made and whether such duress is being exerted."

The evidence he cites is even stronger than that. As he points out, it is important to note that:

"The Victorian Medical Treatment Act 1988 allows citizens to appoint another person of their choice (Medical Power of Attorney or 'agent') to make medical decisions on their behalf if they become unable to make their own decisions. That agent has the legal power to make decisions that can cause or hasten death, by the refusal or withdrawal of life-prolonging treatment. The person appointed may be a family member who is a beneficiary under the estate of

the person whose death is hastened. The Act recognises the possibility that ulterior motive might occur, and includes Section 5F to deal with this. Section 5F states that a beneficiary, under a will, instrument or intestacy, who "by any deception, fraud, mis-statement or undue influence" procures or obtains a [refusal of treatment] certificate, forfeits any interest under the will, instrument or intestacy."

This Section (5f) covers exactly the circumstances that opponents argue would be likely to occur with assisted dying legislation. This safeguard has served well and there is <u>no evidence</u> that it has enabled relatives to abuse the vulnerable as the alarmists predicted.

To quote Dr Syme once again...

"The Medical Treatment Act has been in operation for 25 years, yet the Victorian Police Corporate Statistics Unit finds that here has been no charge in relation to Section 5f during those 25 years. In addition, correspondence from the Victorian Minister of Health, confirms that no investigations or prosecutions have occurred since "no complaints have been received."

An observation about alarmist type predictions by Harvard Professor Steven Pinker is pertinent here:

"For such hypotheses to justify restrictive laws, they need empirical support. In one's imagination, anything can lead to anything else: Allowing people to skip church can lead to indolence; letting women drive can lead to sexual licentiousness. In a free society, one cannot empower the government to outlaw any behaviour that offends someone just because the offendee can pull a hypothetical future injury out of the air."

In contrast to the unsupported fears of the alarmists, the history of <a href="The-Medical Treatment Act 1988">Medical Treatment Act 1988</a> reveals absolutely no evidence that <a href="any">any</a>
predicted hypothetical injury eventuated. Likewise, there is no reason to believe this with medically assisted dying. The bald assertion that "safeguards cannot be effective" does not have any support in fact and is an attempt at scaremongering. The record of Switzerland over more than 70 years and Oregon over 18 years provides the evidence.

**2. Switzerland.** The Switzerland experience over more than 70 years is further robust evidence that safeguards not only can work but they have worked. Under the Swiss penal code that came into effect in 1942, assisting someone to die is permitted, provided one can prove that it is motivated by compassion. In other words the Swiss, in decriminalising suicide also decriminalised the act of assisting a suicide provided that assistance is free from selfish motivation. (Unlike many other jurisdictions, there is no requirement that the person assisting be a doctor and no requirement that the person receiving assistance be terminally ill.)

The Swiss law then, relies on the safeguard that the assistance must not be selfishly motivated – a safeguard that has been in place and worked well for more than 70 years. The Swiss Government in a 2011 report listed four theoretical abuses that could be possible but have not eventuated commenting that:

"As stated previously, theoretically possible abuses in the field of assisted suicide can be effectively prevented by today's Swiss law."9

So the Swiss evidence is that voluntary assisted dying <u>can</u> be regulated and with a simple safeguard prevent greedy relatives exerting duress on an ailing family member to end his/her life prematurely in order to gain the inheritance.

**Oregon.** Oregon has the next longest track record. Oregon's Act effectively began operation in 1997 and requires that patients be terminally ill and must take the medication themselves. The refereed paper by Battin et al (2007) found, after extensive analysis of practice in Oregon (and Netherlands), that there was no evidence of vulnerable groups being disadvantaged or placed under duress.

Further, Justice Lynn Smith presiding over the case of <u>Carter v. Canada</u> in the Supreme Court of British Columbia in 2011 heard extensive expert testimony from doctors and bio-ethicists on the question of duress on the vulnerable, particularly in relation to practice in Oregon and the Netherlands. Her finding:

"I accept that the conclusions stated in the Battin et al. study are soundly based on the data. I find that the empirical evidence gathered in the two jurisdictions does not support the hypothesis that physician-assisted death has imposed a particular risk to socially vulnerable populations. The evidence does support Dr van Delden's (Dutch nursing home physician, bio-ethicist and researcher) position that it is possible for a state to design a system that both permits some individuals to access physician-assisted death and socially protects vulnerable individuals and groups." 12

Again, the evidence contradicts the assertion that assisted dying cannot be regulated with effective safeguards. Each of these sources provides evidence contrary to the fear-mongering predictions.

Nevertheless, seemingly oblivious to the facts, opponents continue to assert that permitting assisted dying will put us on a slippery slope of abuse of the vulnerable.

### **Religious Leaders - Inconvenient Facts.**

A key motivation for ignoring the facts and maintaining this assertion was revealed in an article that appeared in the <u>Daily Mail last year (2014)</u> written by the former Archbishop of Canterbury, Lord Carey. It provides rare insight. He wrote:

"Until recently, I would have fiercely opposed Lord Falconer's [Assisted Dying] Bill. My background in the Christian Church could hardly allow me to do otherwise. I would have used the time-honoured argument that we should be devoting ourselves to care, not killing. I would have paraded all the usual concerns about the risks of 'slippery slopes' and 'state-sponsored euthanasia'. ... The fact is that I have changed my mind. The old philosophical certainties have collapsed in the face of the reality of needless suffering. ... Many of us, whether practicing Christians or not, have used

the term 'merciful release'. If we truly think death can be a form of mercy after suffering, should that thinking not be enshrined in law?"

This points to the fact that the most vociferous opposition comes from the religious hierarchies and religious-backed groups who maintain their stance - seemingly impervious to the facts. To take one example, consider what the now archbishop of Sydney, Anthony Fisher said in 2011:

"We may be standing on the verge of legalising, somewhere in this country, the killing of those who suffer by those who are comfortable, of the vulnerable by the powerful and of the sick by those professed to heal them," 13

# The same Archbishop earlier said:

"we have a wisdom to offer on these matters that is informed by divine revelation as well as long human experience. We do not have to hide our religious petticoats altogether" 14

# **Religious Leaders Unrepresentative of Their Congregations**

In failing to acknowledge the facts and continuing the opposition to any form of legislative reform, the religious leaders also fail to represent the views of the large majority of Australians... or indeed, even their own congregations. NewsPoll shows that three out of four Catholics (74.3%), four out of five Anglicans (81.7%) and more than two out of three (70.0%) of all other Australians of any religion are in favour of voluntary euthanasia law reform. <sup>15</sup>

#### The Status Quo is No Answer

In a secular democracy, we cannot continue to be ruled by the dictates of the church and 'divine revelation'. This tenacious attachment to the status quo is a refusal to come to grips with the fact that, in the absence of a peaceful option, people are taking their lives violently. Too many elderly Australians are taking their own lives violently and alone; in fear of a slow horrific demise and this has a tragic impact on families.

As already noted, to maintain the status quo also ignores the fact that unlawful medical assistance is already practised by doctors. <sup>16,17,18</sup> Even without decriminalisation such assistance will become more widespread under the twin pressures of aging population and advances in medical technology. Current options are not acceptable for everyone and are not covered by any safeguards, which a Bill would provide.

Surely we have moved beyond the dictates of the church to control our laws. Indeed today, a majority of Catholics align with the overwhelming majority of Australians in rejecting the Catholic Church's opposition to assisted dying as they have done on contraception.

In this increasingly secular country, the religious hierarchies work hard to resist this type of change. Yet, it is arguable that decriminalisation of voluntary assisted dying in Victoria, and in the rest of Australia, is inevitable and it is now a question of how much time will elapse and how many people must suffer or die violently in the meantime, before it is enacted.

# **Evidence Not Ideology**

Placing ideology before evidence, opponents of such legislation, at times wilfully or otherwise, distort the facts. A key one, for example, is the statement repeatedly advanced to argue that safeguards don't work, that in the Netherlands, where voluntary euthanasia is legal, "1000 people per year are killed without their consent".

This is distortion of the facts for two reasons:

<u>First</u>, the 1000 figure actually refers to non-voluntary euthanasia also known as 'euthanasia without explicit request'. It means that a doctor, typically in consultation with her colleagues and the patient's family, makes the sad decision that the best thing for the terminal patient is to hasten their death. This *doesn't* mean the patient was never consulted about their wishes. It may simply mean that their wishes were not formally recorded and, at the time of their death, they were not in a position to confirm their request.

<u>Second</u>, this is ancient data from a 1990 study. It is not only grossly misleading to cite figures from a 24 year old paper, it is especially so when that time <u>predated</u> the introduction of the Dutch voluntary euthanasia legislation.

Indeed, this 1000 figure so often quoted is derived from the Lancet in 1991 *before* voluntary euthanasia was legalised in the Netherlands. (Up until then, voluntary euthanasia was tolerated under certain circumstances but was not yet legal.)

Three more recent, peer reviewed studies, Van der Maas et al (1996)<sup>19</sup>, Van der Heide et al (2007)<sup>20</sup> and Onwuteaka-Philipsen et al (2012)<sup>21</sup> have shown lower figures, and in the vast majority of cases, prior discussion had taken place with the patient but was not possible explicitly at the time of death.

Van der Maas et al make it very clear that:

"Further scrutiny of the case histories in the interview study showed that decisions to end life without the patient's request covered a wide range of situations, with a large group of patients having only a few hours or days to live, whereas a small number had a longer life expectancy but were evidently suffering greatly, with verbal contact no longer possible." P1702

#### They also found that:

"The frequency of cases in which life was ended without an explicit request by the patient has decreased somewhat since 1990." P1704

Van der Heide (2007) confirms that deaths 'without explicit request' further decreased from 2001 to 2004. And in the latest study, Onwuteaka-Philipsen et al (2012) found that 2010 was lower again.

The bottom line is that euthanasia 'without explicit request' did not increase in The Netherlands after voluntary euthanasia laws came into effect in 2002. It was reduced – the opposite of what many opponents assert<sup>22</sup>.

#### Conclusion

People ideologically opposed to decriminalisation of voluntary assisted dying have every right to an opinion. However, they are not entitled to invent their own facts. Facts are things that stand independent of what one would 'like to believe'. They are not things to be reformulated in order to be shoehorned into one's narrow ideology.

Should we be careful about aid-in-dying reform? Yes. Should we be vigilant? Yes. But the overwhelming majority of the community should not be denied a choice they believe they should be entitled to, simply because a small section of society holds an unjustified fear of the prospect of reform.

Many of us have watched a grandparent, parent or a close friend die a slow death while pleading for something to speed it up. How utterly unworthy of those opposed to assisted dying legislation to distort this and say that decriminalisation of medically assisted dying will lead to a growing sense of a duty to die.

How undeserving to imply that relatives who are distressed by those terminally ill loved ones, whose suffering is such that they plead for release are pressuring their loved one to die to accommodate their own fatigue or selfish motive.

For ourselves, we want an option to seek and receive medical assistance for a peaceful death if we so choose. Part of that motivation is not just a personal one but a loving one to spare those who are closest to us having to look on as helpless spectators and endure the agony of unnecessarily prolonged suffering.

I urge the committee members not to rely entirely on submissions but to visit the jurisdictions overseas to assess first hand if decriminalisation is working.

<sup>3</sup> Essential Poll <u>"Voluntary Euthanasia</u> May 2015. <u>The Economist/Ipsos MORI poll</u>, June 2015.

<sup>1 &</sup>quot;Palliative Care, Suicide Prevention and Organised Suicidehelp" / Report of the Swiss Federal Government/Berne June 2011, P34/35: \displays 3. I. Background

<sup>&</sup>lt;sup>2</sup> Oregon.gov <u>Death with dignity act</u> annual reports.

Douglas, C D et al, "The intention to hasten death: a survey of attitudes and practices of surgeons in Australia", Medical Journal of Australia 175: 19 November 2001, page 513
 Kuhse, H. and Singer, P. "End-of-life decisions in Australian medical practice". The Medical Journal of Australia, Vol. 148, June 20 1988 page 623-627

<sup>&</sup>lt;sup>6</sup> Stevens, Christine A & Hassan, Riaz, <u>"Management of death, dying and euthanasia:</u> <u>Attitudes and practices of medical practitioners and nurses in South Australia."</u> August 1992

<sup>&</sup>lt;sup>7</sup> Syme, R. "<u>Duress on the 'vulnerable' to end their lives</u>". DWDV Update Newsletter Spring - October 2013, p3

<sup>&</sup>lt;sup>8</sup> Pinker, S. <u>The Stupidity of Dignity: Conservative bioethics' latest, most dangerous ploy</u>. The New Republic May 28, 2008

<sup>10</sup> Oregon.gov Death with dignity act annual reports.

<sup>12</sup> Justice Lynn Smith presiding over the case of <u>Carter v. Canada</u> in the Supreme Court of British Columbia in 2011. Point 667

Fisher, A. Bishop Calls on Judiciary to Join Fight Against Euthanasia Catholic Communications website, Sydney Archdiocese,

Fisher, A. Thoughts on the new euthanasia campaign. Australian Association of Catholic Bioethicists' National Colloquium, Eugenics in Contemporary Bioethics, East Melbourne, 25

January 2011

15 Newspoll national survey (2007), 2,423 respondents, report available at

http://www.dwdv.org.au/Docs/DWD%20Summary%20Newspoll%20Report%202007.pdf Douglas, C D et al, "The intention to hasten death: a survey of attitudes and practices of surgeons in Australia", Medical Journal of Australia 175: 19 November 2001, page 513 Kuhse, H. and Singer, P. "End-of-life decisions in Australian medical practice". The Medical Journal of Australia, Vol. 148, June 20 1988 page 623-627

<sup>18</sup> Stevens, Christine A & Hassan, Riaz, "Management of death, dying and euthanasia: Attitudes and practices of medical practitioners and nurses in South Australia." August 1992 Van der Maas et al (1996) "Euthanasia, Physician-Assisted Suicide, and Other Medical Practices Involving the End of Life in the Netherlands, 1990–1995", New England Journal of

Medicine. V335 No.22:

<sup>20</sup> Van der Heide et al (2007), "End-of-Life Practices in the Netherlands under the Euthanasia Act", New England Journal of Medicine.

Onwuteaka-Philipsen et al (2012) Trends in end-of-life practices before and after the enactment of the euthanasia law in the Netherlands from 1990 to 2010: a repeated crosssectional survey. The Lancet\_Sep 8;380(9845):908-15

Examples of distorting the facts (my bolding):

- a) "Supposed safeguards for euthanasia legislation don't work. In Holland where euthanasia has been practiced since the 1990s, 1000 people per year are killed without their consent. The Dutch experience shows that so-called voluntary euthanasia quickly becomes non-voluntary euthanasia." (Family First policy statement for the Victorian Parliament lower house seat of Melbourne.)
- b) "We should also continue to stand firm in rejecting legislation that would send dreadful messages to the sick and elderly about the worth of their lives and which would put people's lives at risk.
- "For example, in Holland where euthanasia has been legal for some years, research indicates that around 1,000 people are killed each year without their consent." (Australian Christian Lobby media release: Vic Greens wasting parliament's time on euthanasia 11 August 2010.)
- d) In a public forum Your Death, Your Choice on the Sunshine Coast in May 2012, Mr. Geoff Bullock of Family Voice Australia relied on the ACL statement above to declare that after voluntary euthanasia was legalized in The Netherlands, the rate of involuntary euthanasia increased.
- Here is an exert from a paper "Netherlands' euthanasia stats are appalling" that still appears on the website of anti-euthanasia body EuthanasiaNo - dateline 9 July 2012 that says: "Guidelines won't protect us, if the Dutch experience tells us anything....After the guidelines had been in place for 23 years, doctors were surveyed about people they euthanized.... In 1990, 130,000 people died in the Netherlands: 2,300 people asked doctors to kill them; 400 asked doctors to provide them with the means to kill themselves; 8,100 died when doctors deliberately gave them an overdose of pain medication to kill them (for which 4,941 patients didn't consent); 1,040 people died when doctors euthanized them without their knowledge or consent (72 per cent of those never having given any indication they would want their lives terminated)"

<sup>&</sup>lt;sup>9</sup> "Palliative Care, Suicide Prevention and Organised Suicidehelp" / Report of the Swiss Federal Government/Berne June 2011, P34/35: \displays. I. Background

<sup>11</sup> Battin MP et al, <u>Legal physician-assisted dying in Oregon and the Netherlands: evidence</u> concerning the impact on patients in "vulnerable" groups. Journal of Medical Ethics, 2007:10;591

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